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ABSTRACT

This paper recounts the Macomb-Oakland (Michigan) Regional Center's 17-year successful experience in eliminating institutional care for children with developmental disabilities (many of them with severe disabilities) and providing all such children with specialized foster home placements. A paper by the Center's director, Gerald Provencal, describes major features of the Center's community training home program, including in-house programming, contract agreements, interdisciplinary team involvement, recruitment, training, and monitoring, and refutes six common fallacies of objections to the foster care model. Recognition of the importance of providing birth families (as well as foster families) with whatever support is needed is identified as a program outgrowth. The program's success in finding families and in maintaining placements (the average placement is more than 5 years) is then recounted. Further discussion details the process of finding families, including needs assessment, recruitment, initial inquiry call, screening, and training. Also considered are specific recruitment strategies, parental misgivings, professional attitudes, funding, and case management. Various case studies illustrate the report's major points. (DB)

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A CHILD'S BIRTHRIGHT: TO LIVE IN A FAMILY

A Vicarious Visit to

MACOMB-OAKLAND REGIONAL CENTER

Mt. Clemens, Michigan

This paper is distributed through an agreement between the Macomb-Oakland Regional Center, Michigan, and the Research and Training Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, with support from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR) under Cooperative Agreement No. H133B00003-90. No official endorsement by the U.S. Department of Education should be inferred.

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Contributing Authors

Margo Beauregard

Laurel Berger

Candy Cranston

Cyndy Dehem

Sherilynn Kruger

Karen Laird

Jan Maier

Carolyn Mansell

Paul Newman

Margo Bloomfield

Gerald Provencal

Nancy Rosenau

Nancy Tancredi

Theresa Tenbusch

Carol Whelan

Editor: Nancy Rosenau
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ITINERARY

* **WELCOME TO M.O.R.C.** - Pre Tour Orientation. 1

* **INTRODUCING M.O.R.C. AND THE COMMUNITY TRAINING HOME PROGRAM** 2

* **FEATURES OF THE COMMUNITY TRAINING HOME PROGRAM** 3

  - A Fifteen Year History. 4

  - Transition to Birth Family Support. 13

* **EXPLORING THE COMMUNITY TRAINING HOME PROGRAM** 15

  FINDING FAMILIES

  Willingness: Meet Dana 16

  Placement Planning: Meet Connie. 18

  Recruitment Specialization: Meet Sue. 22

  Soup to Nuts Development. 25

  Recruitment Strategies. 29

  Parental Misgivings 32

  SUPPORTING FAMILIES

  What-Ever-It Takes Support: Meet Rusty. 36

  Professional Attitudes: Meet Chelsea. 38

  Funding: Meet David 41

  Casemanagement: Meet Karen. 46

* **GOOD-BYE**

  Rules for the Road. 48

  Then and Now: Meet Krista. 50

WELCOME TO MACOMB-OAKLAND REGIONAL CENTER

Pre-Tour Orientation

We welcome you on this vicarious visit to Macomb-Oakland Regional Center. This tour is a story about change. This is a story about families and kids, and systems, and values. It is a story of immense optimism for the futures of families and kids and systems. It is a story of what's "do-able".
In a short seventeen years for a geographic region of just under 2 million people, institutional life for children with developmental disabilities has become extinct. No children from this large catchment reside in institutions, nursing homes or congregate care settings. In a short seventeen years the human services system that deals with children with severe developmental disabilities was completely and totally reversed from a system that encouraged institutional care to one that despises it; from a system that denied or discouraged support to families to one that recognizes, facilitates, supports and celebrates the capacities and gifts of families and the value of family life to human growth and potential for <u>all</u> children. Growing up in a family has come to be the <u>only</u> accepted "residential" option.

This is the story of how it happened, why it works, and what is needed to replicate it anywhere in the world. Welcome and enjoy your visit.

INTRODUCING MORC AND THE COMMUNITY TRAINING HOME PROGRAM

Macomb-Oakland Regional Center is a state agency of the Michigan Department of Mental Health. Originally it was created to be an institution to serve a waiting list of people with developmental disabilities who needed residential situations. Instead, through visionary leadership and hard work, it became a model for community based alternatives to institutional care.

In the course of debunking the institution as a residential choice, part of the work of the agency focused on children.

After early successes in placing severely disabled children from institutions into foster care family situations, the agency set about finding homes for every child, one-at-a-time. In the course of that endeavor many lessons were learned about how to support families, about the capacities of families, about the capacities of children, and about dramatic results that perpetuated the effort and endorsed the rightness of the outcome:

a <u>family</u> for <u>every</u> child

In the course of seventeen years of effort and a willingness to provide "What-ever-it-takes" support, we have found <u>NO</u> child with a disability too severe to live with a family, and <u>NO</u> child who was not wanted by someone.

We have learned many, many lessons. We want to share here the most important ones. We believe they describe and prescribe what it takes to be able to make good on the claim that: "All children can and should live with families".

To support the weight of the lessons, we felt it important to meet some real kids, and real families, and real workers in a real system. The accompanying stories not only describe how a child came to have a family life, but describe

how we learned how to make that possible. These are some of the many people you would meet on a visit to MORC. We hope through their stories you will be able to experience this vicarious visit.

FEATURES OF THE COMMUNITY TRAINING HOME PROGRAM

A Fifteen Year History

In visiting M.O.R.C. you might first meet its director, Jerry Provencal. Jerry would share with you a perspective of M.O.R.C.'s history. The address which follows was presented by Jerry Provencal at the Fifth International Foster Care Conference in Leeds, England in August 1987. It details the experience of the Community Training Home program fifteen years after its organization. It reiterates the principles that are the foundation for its success. It vividly refutes the common misconceptions held by critics and skeptics about the "do-ability" of the effort.

Of particular note are the statistics and data presented which demonstrate the strength, stability and longevity of the program which enables families to do what they do best: raise children, **all** children.

SPECIALIZED FOSTER CARE FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES - FIFTEEN YEAR HISTORY

Gerald Provencal

Since 1972 the Macomb-Oakland Regional Center has been an agency working on a mission, and working with the conviction that we can make an unequivocal difference in the lives of people with developmental disabilities. As a part of this mission, we have developed a second objective and that is to make traditional institutions an obsolete feature of the lives of people in this population.

In our quest to satisfy both ambitions, we have examined every known housing and support service model that has been used for populations that have any similarity to people with developmental disabilities. One institutional alternative we explored early on in our campaign, and are now making heavy use of, is foster care.

What we found nationally in 1972 was that while the number of institutionalized people finding new homes in the larger community had been increasing, foster homes remained the least used of the major residential possibilities, behind nursing homes and group homes.

That foster homes should occupy such a lowly position was somewhat puzzling. In keeping with the principle of normalization, it would have seemed that the qualities inherent in a small foster home would be strongly championed by professionals. Certainly, for children, any comparison between foster home and group home characteristics must find the former in closer proximity than the latter to the Wolfensberger definition of normalization. . .

> "Utilization of means which are culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are culturally normative as possible."

Rather than promoting foster home strengths, however, we found professionals frequently turned attention toward its limitations. The following were six commonly attributed weaknesses of foster homes:

> "It's impossible to find good foster parents in significant numbers."
>
> "Foster parents can only cope with easy clients."
>
> "Foster parents might give love and good physical care, but they can't be expected to teach."
>
> "Foster homes are too difficult to monitor."
>
> "Birth families will never accept it."
>
> "Foster parents will burn themselves out with this population."

This paper will discuss ways in which we set about to either correct a misperception about foster care or improve on a weakness of its structure.

The discussion chronicles the 15 year maturation of MORC's innovative variation of the foster home concept. Specifically, it describes the Community Training Home of MORC. The features which make this model different from the traditional foster home and provide the basis for its increased potential as an institutional alternative are discussed in detail.

1. PROMINENT FEATURES OF MORC'S COMMUNITY TRAINING HOME PROGRAM

In-House Programming

One of the constant companions of foster parents has always been meager payment for services. In Michigan in 1969 this equaled $4.28 per day. The common inadequacy of remuneration was put this way by a New Jersey woman. "The money the state pays is barely enough to manage and does not compensate for the time and attention (which) should be given to the three new members of (my) family. I do it because I like it, and I'll keep doing it until I can't. But don't get in it unless your heart is in it."

The recognition that payment for services was inadequate, when combined with the criticisms leveled by professionals that foster parents lack training and primarily offer only tender loving care, helped bring about a partial solution to both problems.

We embarked on a pilot project to develop a specialized foster care program which made a separate distinction between room, board and supervision and a new category of foster parent services called "in-house programming." The expectations of room, board and supervision remained as they always had been: essentially to provide housing, meals and guidance to a resident. In-house programming, on the other hand, encompassed an entirely new set of expectations. Foster parents were to be regarded as trainers implementing a specific skill acquisition program for each individual who came to live with them and they were compensated financially for the delivery of this service.

Contract Agreement

In order to assure clear understanding of responsibilities, a contractual agreement was drawn up between the agency and the foster parents. Specific habilitative objectives became a part of the program contract.

Documentation of the delivery of the services became part of the ongoing responsibility of the foster parent and is done so on a monthly basis. While this made the auditors happy, it also had a secondary benefit to foster parents.

Rather than perceiving monthly reporting to the social worker as useless paperwork, foster parents took this opportunity to give themselves credit for all the effort they had in fact put in with the resident. This scheduled requirement of recording client progress, activity and overall status was typically seen by the foster parent as a direct reflection of their commitment to the client.

Interdisciplinary Team Involvement

The development of the specific elements of the in-house program was done with the involvement of an interdisciplinary team of professionals assigned to each home. Specific behavioral objectives, linked to habilitative goals were selected by the interdisciplinary team for each resident. The focus of the

training program was determined by the individual needs of the resident. The team was headed by a casemanager. The expectation of the casemanager was to make frequent visits in the family's home to provide support, direction, and to oversee the program plan. An average of 25 visits per year with the casemanager was a routine expectation. In addition, other professionals from the team would visit as needed.

The combination of separate payment for in-house programming, monthly reporting of effort spent on the behalf of the resident and frequent visitation by the casemanager and other professionals has upgraded the service rendered the client as well as the relationship between the agency and the foster parent.

A clear advantage became apparent. Both team members and foster parents alike appeared to raise the expectations they held for one another's behavior. The contract, bolstered by the frequency of written reporting and meetings for progress review, required more from each than was the case in more traditional foster home models.

In the Community Training Home model, foster parents came to be regarded as paraprofessionals. They frequently became so skilled and knowledgeable about clients, that team members responded to them as most skilled coequal colleagues.

By making consultants accessible for in-home programming and providing extensive ongoing foster parent training, the client was assured quality follow-along. By making themselves available for referral, the consultants helped the client integration process by supporting service acquisition from community-based resources. Each assurance brought by the consultant group resulted in the foster parent feeling more secure in backup and better directed in their contribution of in-house programming and more secure in their ability to handle clients with challenges. The martyrdom so common to traditional foster parents was replaced by a more equitable recognition of the shared responsibility and reward.

Recruitment

Foster care as an institutional alternative had historically suffered from an image problem. In order to maximize its potential, it became clear that foster parents' roles needed a rather dramatic upgrading. With the addition of the in-house programming concept, accompanied by payment and skill training, the position of the foster parent took on an increased respectability. A direct benefit of improving the image and rewards of foster parenting was that possibilities for recruitment took on a new optimistic dimension. Enhancing the image increased the likelihood that families once found, would be more accepting. The task became finding enough families.

That the Macomb-Oakland Regional Center program had consistently good recruitment results was in significant measure, attributed to the creation of a specialty "development staff". Their roles and time were protected from secondary assignments. Development staff were able to perfect a variety of techniques to hone their specialty. Their task was to reach as many potential foster families as possible.

Of the several productive methods utilized to reach potential recruits, none proved as consistently effective as the classified ad. Before actually demerits of this approach were discussed at great length. Whether such a

placing the first advertisement in a local daily newspaper, the merits and method would compromise the integrity of mentally retarded persons, or whether it could be presented in such a way as to be respectfully received, were questions that were debated well into many nights. The eventual decision to utilize "want ads" was primarily based upon the belief that, if worded properly, the message would communicate that the advertisement was for a job and not benevolence.

The experiment was an unqualified success. The "Charity" model or the "You must be a saint. . ." model were never effective. A "want ad" attracted people looking for a job and income. The absence of "mental retardation" within the text of the ad was quite deliberate. The reason for the omission was that it gave recruitment workers an important opportunity to talk with people who might otherwise avoid making an inquiry because of misconceptions about mental retardation. This opportunity was very beneficial in that it allowed the time and place for painting an accurate description of both mentally retarded persons and the responsibilities which are a part of being a foster parent.

While some questions were raised about the matter of emphasizing monetary advantages to foster care, the emphasis served an important purpose. The strains, demands and the general difficulties of working with retarded persons undoubtedly occurred to the inquiring party without coaxing. Too often the introduction to this kind of program has been by way of its difficulty and its privation requirements rather than its benefits. Experience has shown that people who enjoy the monetary rewards of the job can also make good foster parents. Simply wanting to earn money for a job well done is not necessarily mercenary nor distasteful. A combination of working for personal satisfaction and income proved most successful.

In addition to want ads MORC mounted an aggressive campaign to publish good media coverage about people with developmental disabilities. Each year an average of 100 separate Macomb-Oakland Regional Center news stories appeared in local newspapers. While most of these stories focused upon some new development within the agency, all highlighted community placement. Invariably with each of these articles there was an opportunity to speak with the reporter preparing the story. Such contact afforded a good opportunity to give information about the campaign for foster parent recruitment, positive community Training Home features and the successful adjustments of clients who have reentered the greater community. On numerous occasions, extensive articles subsequently followed which were exclusively devoted to the variety of challenges and rewards inherent to the foster care program. Again, as with so many other approaches, the gains were measured in positive changes in public attitudes as well as new homes.

While the varied recruitment approaches interested large numbers of people in the Community Training Home program, a relatively small number of individuals were actually accepted. In the words of an experienced development staff member: "We interview individuals who are applying for a rewarding, important yet extremely demanding job. We look for people who are able to raise adults not children. People like that are not easy to find but they can be found."

Training

The degree of emphasis given to preparing foster parents for their job in the Macomb-Oakland Regional Center model differed significantly from many other deinstitutionalization efforts. The American Association on Mental

Deficiencies Mental Retardation publication helps in underscoring this difference. A review of the table of contents of that periodical, reflected a better than twenty-to-one ratio of articles which describe preparing the client to move to the community in contrast to articles which describe the potential care providers - (natural, foster, group home parents) to receive the client. What we did at MORC was to reverse the readiness criteria. While not curtailing client readiness programming, we placed much more attention upon readying natural or surrogate parents to live and work with the individual who was reentering the greater community.

Experience at the Macomb-Oakland Regional Center led to the belief that the likelihood of a client making a successful adjustment in community placement was dependent more upon the degree to which the parent was prepared than the degree to which the client was readied. There emerged no absolutely essential client skills, intellectual levels, or behavioral controls which were prerequisites to successful community adjustment. What emerged as essential was simply that the parent, whether natural or surrogate, must have been prepared emotionally, intellectually and behaviorally to accept the client where the client was.

This recognition led to a strong emphasis on training of the foster parent. The linkage between foster parent training and in-house programming for clients was obviously a critical one. The individual objectives which made up the heart of the program contract could only be pursued by people who had a foundation of skill training. It was difficult to imagine one being present without the other. Clearly, the intent and emphasis of this education/training and in-house programming was to radically alter the misconception of foster parents being limited in giving specialized program delivery.

Monitoring

Historically it has been difficult to monitor foster homes in the more traditional model. The difficulty was not because satisfactory provision of room, board or supervision was too elusive to determine; rather it was hard for the social worker to be critical about what he or she saw. As one social worker pointed out a few years ago: "It is very hard to correct a foster parent for 'spoiling' a resident when she gets about the same amount of money to care for that boy as it costs to board your dog."

The added funding and formal contractual agreement between foster parent and service agency in the MORC program gave the casemanager a more defensible vantage point from which to monitor foster parent influence on the client. This included the effect of subtle nuances as well as more open action and reaction patterns.

In addition to the in-house program contract, which introduced a positive monitoring advantage to the role of the casemanager, there were far more opportunities for observation and interactions of other professionals in the family home where programming was developed, reviewed, and refined regularly.

A single theme was maintained throughout the development of the Community Training Home program. All promotional efforts highlighted the advantages of the job and not the plight of the retarded. There is a substantial difference between the two. Whatever the particular medium used, emphasis was consistently directed toward the benefits and rewards of foster care in the Macomb-Oakland Regional Center program. Mentally retarded persons were never,

under any circumstances, made to appear in desperate need of charity or personal sacrifice. This fact assured both the maintenance of respect and dignity for clients as well as established a context for the future relationship with the foster parents.

The fifteen years since the Macomb-Oakland Regional Center refurbished the traditional foster home model over 375 Community Training Homes have been developed. Obviously, the limitations too frequently attributed to foster care can't all be true to have developed so many homes. I would like to share our experience about each of those six purported limitations, which were cited as reasons why foster care could not work.

FACT VS FICTION; REFUTING COMMON FALLACIES OF THE FOSTER CARE MODEL

Fiction #1: It's impossible to find Good Foster Parents in Significant Numbers.

Upgrading the status of foster parenting coupled with specialization of recruitment roles and marketing, rather than charity-like approaches, resulted in the home development staff generating hundreds of calls per year. Sufficient interest was elicited so that staff had the luxury of being so selective as to accept only two out of every 100 initial applicants.

Fact: In support of our contention that you can find good families and lots of them:

Today we have 155 homes serving 251 people.

We have developed over 375 homes.

From a population of just under 2,000,000 only 11 children do not live with families. Only six live in settings larger than six and they have foster care placements identified and will be placed soon.

Contrast this with the Hamlet-like choice of years ago for families - "to institutionalize or not to institutionalize."

Fiction #2: Foster Parents Can Only Cope with Easy Clients

MORC's Community Training Home program consistently served those people whose needs were considered most challenging. Over 200 people, both children and adults, left institutions to be placed in specialized foster care.

Fact: Supporting the fact that foster parents can and do deal with folks not considered "easy":

70% of the people served in the Community Training Home program have been Severely and Profoundly Retarded.

60% of the people placed have had behavioral challenges.

50% have had medical challenges.

There have been no institutional admissions from a catchment area of 2,000,000 since 1977, 41% of all new admissions go to Community Training Homes. (The others go to other types of Community Placement).

Only one person was ever returned to the institution from a community training home.

Fiction#3: Foster Parents might give Love and Good Physical Care, but they can't be expected to teach.

By building into the program an expectation of foster parent teaching and providing foster parents the tools to teach, that is training and professional input, direction and assistance, the outcome was clear and measurable growth for clients.

Fact: In support of the foster parents' teaching success:

An average of 33 new skills were learned by residents.

Fiction #4: Foster Homes are Difficult to Monitor:

The expectation of in-house programming and the resulting increased role of professionals in the foster family's home provided increased visibility into the day to day life of the residents.

Fact: In support of our contention that foster homes can be effectively monitored.

Over 10,800 visits have been made by professionals staff to Community Training Homes.

Fiction #5: Birth Families Will Never Accept It

When suggesting to natural parents that their son or daughter might be well suited for a foster home, it is not unusual to experience stronger opposition to this than to any other type of placement. "If he can't be cared for in his own home - and we have tried everything - how can he be cared for in someone else's home?" is a typical initial response from birth parents presented with a foster care alternative.

However, when natural families are given an opportunity to become thoroughly familiar with a well-supported and well-monitored Community Training Home, they come to see it as desirable and the placement of choice.

Natural parents and guardians have become so accepting of the program that after visitations with foster parents in their individual Community Training Home and a review of all features of the program, rejection of the placement is virtually nonexistent.

Fact: In support of the acceptance of birth families:

We have only placed over parental objection one time, out of 2,106 placements.

Fiction #6: Foster Parents will burn themselves out with this population.

A final limitation suggested about foster care is a belief that it does not last over the long haul, particularly with care of persons considered to have some notable challenges. Our experience has not shown this. When well supported, adequately compensated, meaningfully trained, and systematically nurtured by administrative policies, the foster care model has proven to be one of substantial longevity.

Fact: In demonstration of the potential longevity of foster parents:

Since MORC's creation fifteen years ago, four families still have the developmentally disabled members who came to share their home fifteen years ago.

50 families have provided homes for a developmentally disabled member for more than ten years.

The average length of stay in a Community Training Home is five years.

As a testimonial to the desirability of the role as perceived by foster parents, some of the best recruiters of new homes are existing foster parents.

45 homes have been developed by referral or friends and neighbors of existing homes.

15 homes are second or third generation families.

CONCLUSION

When examining the strengths and limitations of the community training home, it is understood that inevitably someone will find an example to detract from design or structure. With this, as any other model, one hundred reasons can be given the concept being unworkable. The fact of the matter is, however, that it has worked and worked well.

In the Macomb-Oakland Regional Center menu of institutional alternatives the Community Training Home is not in last but first place in number of children in residence. It is also viewed as the preferred option outside of the natural home.

The Community Training Home is certainly not the single answer to community placement. Much more work must be directed toward supporting natural home living, and additional models for specialized living arrangements for adults are obviously required before we can even begin to get within reaching distance of our goal of obsolescence of institutions.

Our experience with the Community Training Home model has proven it to be a desirable normative setting, adaptable to a multiplicity of needs. Much of the model's potential as a residential alternative lies within its capacity to

be both versatile to the agency and sensitive to the individual.

After fifteen years of experience, we now have the hard evidence:

Virtually any child with a developmental disability can live a warm, enriching life with a family if the family has been:

Selected with care.

Prepared with respect.

Supported with vigor.

Jerry Provencal
August, 1987

FEATURES OF THE COMMUNITY TRAINING HOME PROGRAM

Transition to Birth Family Support

While this tour is about foster families, it is vital to recognize the lessons learned from foster families taught us how to support any family. We came to recognize from foster families that (1) kids need to grow up in families for emotional health, (2) families are willing and (3) success is only dependent on the development of appropriate and adequate supports. It was only a logical extension to apply this thinking to birth families and avoid an out-of-home placement to begin with.

Our work in figuring out how to support foster families taught us how to support birth families. We came to recognize the "whatever-it-takes" position applies to supports for birth families as well. When we extended the same creativity and energy to supporting birth families we were able to turn around the referral process to a support process. We no longer were willing to accept that a child was "eligible" for placement because of a severe developmental disability. Instead we asked families: "what would it take to enable you to hold your family together and to function like a family?" We have worked diligently at preventing new admissions, while simultaneously rescuing children from the institutional settings where they had been placed before their families had been extended the opportunities of this new attitude, mind set, and redirection of resources. Our ability to claim no facility placement for children is a result of closing the front door to institutional admissions, as much as opening the back door to let them out.

Our success with foster families was the key to our later success with supporting birth families. Partly this is true because foster families got us to see what really was supportive to them. They helped us see that support has to be on their terms, not ours; that it has to be available on a minute's

notice, in sufficient quality and quantity to be perceived as helpful; and that it does not always or even most importantly cost money. Of course we needed to build ramps, buy wheelchairs, outfit vans, hire home-care nurses, pay respite providers, and trainers. But, what families reported was important was knowing there was an agency behind them, personified in a casemanager whose home phone number was posted on their refrigerator and who didn't mind being called in the middle of the night or coming out on a Sunday, and talking over a cup of coffee for a couple hours about a strategy to solve a problem together.

We came to realize that we learned from foster families because we had to listen to foster families. Our success was directly connected to our meeting of their needs. And to meet what they needed we had to listen, and if we didn't listen we would lose them and ultimately would have a child with no place to go. We were (appropriately and willingly) "hostages" to our foster families. Several hundred families later we have never felt taken advantage of. On the contrary, families are extremely conservative and don't ask for more than they need. In fact, they would rather "do it their way" than seek agency intervention. When we began to risk asking the "what-do-you-need" question of birth families, we experienced the same phenomena. The bureaucrats nightmare that opening the door would break the bank simply did not materialize.

In 1980 our work in supporting foster families led us to apply for a demonstration grant project where we provided to birth families everything we provided for foster families, including cash. This was the precursor to what followed in 1984 when Michigan passed the Family Support Subsidy legislation which provides cash assistance for every family with a severely mentally, multiply, or autistically impaired child.

This landmark legislation was a dramatic sign that as a system, we had gotten by the incredible barriers that prevented support to birth families.

EXPLORING THE COMMUNITY TRAINING HOME

The work of connecting families and children falls simply into two areas:

Finding families
Supporting families

On the following guided tour, we will introduce you to some of the issues that apply to each of these areas in order to have a well-rounded view. We'll also stop along the way to visit with a few friends who can describe the customs of the program first hand.

We think some of the things we've found helpful in finding families touch on the following areas:

Willingness

Placement Planning

Recruitment Specialization

Development

Recruitment Strategies

Parental Misgivings

We think some of the things we've found helpful in supporting families are in the following areas:

What-ever-it-takes-Support

Professional Attitudes

Funding

Casemanagement

FINDING FAMILIES

Willingness: Meet Dana

We learned from families as we went along. We learned that families are willing to accept children with all kinds of disabilities. In our early years, we started by looking for families willing to take the children we thought were "placeable". Placeable children tended to be the young children, the cute children, the children with less complex medical and behavioral challenges. In our early days we did not admit, but probably secretly felt, that there were some kids who were just too complex or too unappealing to find a family willing to accept them. But we quickly learned we had underestimated the capacity of families to love. Sooner or later we found a family for every child simply by introducing families to kids who needed homes.

Our approach was one-at-a-time. By recruiting lots of families, we had lots of opportunities to make the connections that ultimately clicked. Today we have a waiting list of families for whom we have no children waiting. Let's meet Dana. Her story depicts this vividly.

Meet Dana

As a "seasoned professional", I was sure that because I had seen so many things in my work experiences, very little could shock me. However, nothing in my previous experience prepared me for what I would see the first time I entered a pediatric nursing facility.

Two nurses and I had been asked to visit the nursing center, to meet the children who lived there in order to prepare recommendations for alternative living environments. The three of us met at the nursing center, intent on meeting all of the residents on one day. We went into rooms and found two children in bed, we went into other rooms where we'd find one child left alone lying in bed, we entered rooms with six or eight cribs lining the walls, all with children lying in bed. The rooms were drab and sad and empty feeling.

The visual images of that day are overwhelming in the strength of their

memory. Children of all ages, doing absolutely nothing that typical children do. There were no opportunities for free movement, for playing, for silliness, for laughter. There was little free physical contact. . . no hugging, no playing tag, no wrestling, no reassuring hands on shoulders. There were children reaching out of cribs toward us, total strangers in their "home". There were children laying on the floor, not able to reach out, not able to call out, left to stare at the feet of passersby, unable to move out of the position they were left in. There were children lying in their cribs and beds, unable to interact with people, friends, families, dogs, toys. There were children with a sad, sickly pallor that made it clear to the observer that they hadn't seen fresh air and sunlight in many days.

This "seasoned professional" felt every emotion that I was unprepared for that day. The experience became overpowering for all of us, almost all at once. I remember one of my companions looking at me with the puzzled, hurt look that I am sure I was mirroring. We retreated to the lobby of the geriatric area on the lower floor and sat for about half an hour to regroup. The visceral reactions to what we had seen were common to all of us . . . nervousness, nausea, light-headedness, tears rapidly welling in our eyes. All of those feelings suddenly converted to anger . . . we can't let these children grow up like this . . . think of the families that would love to have any one of these children . . . they're only kids, look at the kind of life they're living . . . it isn't fair . . . they deserve a home, brothers and sisters to fight with, family stuff . . . just imagine what it must be like to live here . . .

We forced ourselves to go back upstairs to finish what we had come to do. In one of the last rooms, a little girl was lying on a mat on the floor. She had pretty blond hair and lay facing away from me. I walked around her to say hello and found that I could not approach her. Her face and head were severely disfigured by a massive growth that protruded about four inches from her forehead and pushed her eyes into the wrong place on her face. I stepped back, left the room, and leaned against the wall in the hallway, thinking I might soon find myself on the floor. I was shocked at her appearance, but moreso, I was disappointed at my reaction to her. I knew she deserved better from me, that she was just a little girl, another child who needed more than what she was getting. I took a deep breath, went back in the room and introduced myself. We talked for awhile, then I saw a sparkle arise in the most beautiful blue eyes I had ever seen. Eyes that haunted me on my drive home, remained with me, and continued to push me to find families for children who deserve better from us.

About six months later, I was introduced through one of my colleagues to a young, single woman who had recently become a foster parent to a child from that same nursing center. The foster mom introduced me to her foster daughter and pride radiated from her face. Sitting in the shiny new wheelchair, covered in bright royal blue fabric with a colorful balloon design, was a little girl dressed in a pink and purple sweatsuit with matching barrettes, matching leg warmers, and matching high-top tennis shoes . . . and it was obvious that she was loved and felt loved. Smiling and laughing at the sound of her foster mother's voice, whining and clearly asking to be held and picked up, enjoying the ride, the sights, the people. It was the little girl with

the beautiful blue eyes. Her face was the same, her handicaps were the same, but her life, how her life had changed. She had a mom, she had a grandma and grandpa, she rode in a car every day, she went outside in all sorts of weather, she went to a community school, she went to the mall, she drank Slurpies, and loved McDonalds. She was beginning to see the world like a kid should.

The contrasts between life in the nursing center and life in her home were so glaring. The people at the center were good people who gave their best efforts to provide care. The difference is in the place where life occurs, in the freedom to grow up like any little girl or boy should, in being part of a family that gives love unconditionally and would go to the ends of the earth to provide what they know is right. It's all about having a life, having a home, and having a family. It's all about having a regular childhood, like a regular kid.

FINDING FAMILIES

Placement Planning: Meet Connie

A frequent criticism of foster care is its lack of stability over time. Large foster care systems are notorious for children bouncing from home to home.

Our experience with foster care has been distinctly different. The average length of stay in a foster placement has been more than five years.

A key to the success of finding homes that last over time is the amount of time and energy that go into the process of matching children with the right home and preparing the home adequately.

A distinct difference in placing children with developmental disabilities which distinguishes it from the typical child welfare system is that the usual placement has more time for planning than an abused child who needs to be removed from the home with little warning or planning. While we view with a strong sense of urgency a child needing to leave an institutional setting, we also take the time to choose a family carefully and do preparatory training and work with the foster family before placement. A child leaving his own

home is in a situation where first attempts should be to train and buoy up the birth home, which simultaneously leaves lead time to prepare a foster family in the event supports are unsuccessful. Often times a birth family, who can see relief in sight will "hold-on" a little longer if they can learn to see the time is being well spent in preparation to assure a good and stable placement situation.

Placement planning has a number of parts to it. First is the phase where introduction of the child and family occurs. We have come to look for immediate signs of attraction as a prerequisite to a successful placement.

Our experience with hundreds of foster families has proven that initial reactions are the best predictors of success. While not a scientific description, "love-at-first-sight" is a phenomena well recognized by veteran workers. Where an initial attraction does not occur, it can't be forced. It is the basis upon which training and adjusting of life-styles is built and succeeds.

The second phase of placement planning is exposure in increasing amounts of time. Following an initial reaction that is positive, the foster family needs to have plenty of opportunities to be with the child. These can be visits where the child lives, followed by short visits to the foster home, followed by longer and sometimes protracted visits to the foster home before a final placement decision is made.

The third phase of placement planning is the teaching phase. Under the guidance of an interdisciplinary team, a set of training objectives and strategies are outlined that address all of the unique and individual specific needs of the child.

The fourth phase of placement planning is the procurement phase. This is the phase where equipment, home modifications, household schedule adjustment, and lining up of outside helpers, if necessary, occurs.

The final phase of placement planning is the agreement phase. At this point the foster family, birth family, staff who have been working with child, and staff who will be working with the child sit down together and go over all aspects of the preparation and expectations for the future. In order to be very clear about who will do what and what future actions need to occur, a three way written agreement is drawn up between agency staff, birth, and foster family.

Connie's story describes the placement planning process.

Meet Connie

Now we've really gone too far. That's what I thought when I took the stand in a courtroom up against a formidable team of specialists. We were in court to try to argue why Connie should not be sent to an out-of-state facility that specialized in serving people with her very unique disability. We met Connie on the psychiatric unit of the University Hospital. She was fifteen years old and had been admitted because of uncontrolled behavior which seemed to be driven by hallucinations. After lengthy evaluations, a diagnosis of juvenile onset Huntington's Chorea was made. Connie's only family, her mother, was already incapacitated in a nursing home with Huntington's Chorea. Connie was a state ward, and now a state ward with no place to live.

The hospital staff had investigated treatment settings all over the country and found a nursing home in Minnesota that "specialized in people with Huntington's". Never mind that juvenile onset is very unusual and that Connie would be the only child in this facility. The hospital team was strongly recommending the special treatment setting. The psychiatrist, the psychiatric nurse, and the psychiatric social worker all provided testimony supporting that recommendation, just before I was to take the stand. My testimony would rely on one other characteristic of Connie's, her birthdate. We believe strongly that children should grow up in families and that Connie was a child and needed the nurturing, loving, safe environment of a well supported family, not a 150 bed nursing home in another state where everyone is old and has the same disabilities. But having given that testimony with as much confidence as I could muster, the judge gave us thirty days to make good on the belief and

24 BEST COPY AVAILABLE

arrange a family situation to bring back to court, or the transfer out of state would be made.

I left the court room wondering just how we were going to pull this off. Here was Connie who needed a family desperately. But here was Connie, fifteen years old. Everybody knows its difficult to find a family for a teenager. But add to that, a teenager who has aggressive and destructive behavior, and who has wild hallucinations. Add to that that Connie was black. Add to that what we learned about Huntington's Chorea, that Connie would not always have the aggressive behavior, but because of the degenerative nature of the disease, she would become so weak as to be unable to walk and would lose all of her self care skills. Add to that that her prognosis was terminal and that she would die within a few years. I thought maybe this time our idealism had outstripped the realities of this situation.

But I hadn't yet met Mrs. Bibbs. She was on the waiting list of foster families and had been through the licensing and general training. We talked with her about Connie and the future that awaited her. Mrs. Bibbs agreed to meet her. As she walked onto the hallway of the psych unit, Connie saw her and called out the name of her aunt. Connie thought she looked like her aunt. You could see it happen right there, the bond that would allow all the training and life changes Mrs. Bibbs and her family would go through to make sure Connie could live in a family.

We hurried excitedly back home to begin preparations. The occupational therapist went out to Mrs. Bibbs home to decide how to prepare it to accept the wheelchair that Connie would need in the future. The psychologist researched Connie's records and consulted with the hospital staff, then met with Mrs. Bibbs a number of times to provide strategies for how to handle her aggression and respond to her hallucinations. The nurse joined those discussions to outline the health care issues that accompanied the care that Connie would need. The casemanager worked with the team and Mrs. Bibbs to try and anticipate what she would need. The team met with the Bibb's extended family and agreed to a sharing of care responsibilities. They agreed that, in addition, a built in respite system would be important to support the family. Fifteen hours a week were authorized and built into Mrs. Bibbs contract to allow her to use as she needed. And all through the planning, lots of visits to the hopsital were made to let Connie and the Bibbs family get to know each other. Their commitment became stronger with each visit.

We were able to walk into court a month later and deliver the goods. I told the Judge of the preparations we had made and were prepared to continue. And then Mrs. Bibbs took the stand and explained with simplicity and grace, the home she would make for Connie. After that there really was no question. The court endorsed the plan and Connie had a family.

About a year later, Mrs. Bibbs began the adoption proceedings to make this "unplaceable" child a permanent member of the Bibbs family. Connie did not live long enough for the adoption to be finalized, but she died knowing she had a loving family and that she belonged.

FINDING FAMILIES

Recruitment Specialization: Meet Sue

At MDRC we believe in foster care. We, consequently, make foster family recruitment a priority. Several staff have, as their sole job responsibility, the finding and screening prospective foster families. These home developers have become experts at assessing the potential of applicants and balancing the "screening-out" portion of their task with the equally important, but often overlooked, function of encouraging and nurturing people through the process.

Many other agencies make recruitment a part-time function of staff who already carry a caseload or have multiple other assignments. Conflicting goals can result in diluting the time and expertise needed for recruitment and screening. Casemanagers who also recruit have a disincentive to add new people to the program, as it may have a direct bearing on their future work load. It is in their best interest to find families who they feel will be easiest to work with in the future. A non-specialist may have a tendency to screen out people who do not fit the traditional family model.

Developers, however, seek to look beyond the obvious. They have learned that the two parent "Ozzie and Harriet" family with a house in suburbia is not a requirement for fostering. Many excellent foster parents are single and of every age, income, and educational category. Prerequisite criteria is goodness, decency, and a wish to be a family. Given sufficient time, energy, and money, where the foundation is solid, all other needed elements can be bought, taught or brought to a family. A potentially wonderful foster family may not necessarily have all the needed skills when they apply. But developers whose sole job is developing homes, have the time and

responsibility to work with applicants individually, providing special assistance in areas where it is needed. A developer may take an applicant, who has no experience working with children who have handicaps, to meet existing foster families in order to help the applicant understand what fostering these children entails. A developer can arrange an aggressive schedule to expose the applicant to children. A developer may also help a prospective foster parent locate a new home when his or her current home is unsuitable, or find a new job with hours more conducive with fostering requirements.

Treating every applicant as a potential treasure deserving one's full attention cannot be accomplished by part-time developers who are distracted by competing forces. The personal touch lets prospective foster families know they are needed and respected. More effectively than with words, it teaches them our agency believes in the gifts that families have to offer that make them worthy of our full commitment of time and energy.

Meet Sue

Sue was, on the surface, an unlikely foster mother. A shy, 25 year old who barely spoke above a whisper when we first met her, she lived with her own mother. She had never been married and had no children. She had been working as a nurses aide in a pediatric nursing home since she was eighteen. She loved kids. In particular, she loved Dana. She was working the day Dana was admitted at three weeks of age. Dana was not supposed to live because of the severity of her brain damage. That was seven years ago. Sue worked with Dana whenever she could. Dana responded to her more than other caregivers. Dana knew when Sue was taking care of her and would not eat for strangers. The relationship grew. Sue routinely came to the nursing home on her days off, in order to hold and rock Dana and to feed and play with her. Dana's family came to trust Sue and requested that she be her assigned staff whenever she was on duty. It was only natural, when we met Sue and Dana to ask how we could help them live together.

We recognized that many obstacles existed. However, Sue's long term devotion to Dana made it absolutely clear that helping her provide a home for Dana was

worth the effort. With Sue, our mission was to make it happen. We saw ourselves as conspirators against the stereotype of the traditional foster parent.

Sue's parents did not wish her to bring Dana home to their house to live with them. So the first hurdle was to find a place for Sue to live. Because a nurses aide salary is pretty meager, we had to work with the apartment management to assure the additional income from foster care would qualify her to make it possible. The second hurdle was to find a different job with hours that would coincide with Dana's school schedule so Sue could be home when Dana was. Sue was able to get a job as a-para-professional in the special education program where Dana would go to school. While waiting for an apartment vacancy, we started on the licensing paperwork - filling out applications, obtaining references and medical clearances and interviewing Sue at great length, getting to know her very well and teaching her what expectations we would have of her as a foster parent.

Since Sue would be living alone, she would need an alternate caregiver to be available when Sue could not. She would also need regular built in respite to provide a break from Dana's care from time to time and to allow her to carry on the routine business of life. In addition to the foster care payment we made for Dana's care, we also built into her foster care rate an allowance for arranging for a respite worker with the understanding that Sue could use this in any fashion that worked for her.

Dana's birth family was originally skeptical about foster care, but when they understood who we were proposing, they gladly agreed. They had come to know Sue was the person they counted on to safeguard their daughter at the nursing home and they were pleased to have her as Dana's primary caregiver. For Sue, she not only made an almost equivalent salary from foster care as she had made at the nursing home, she was able to do what she loved best in the world and that was to be with Dana.

FINDING FAMILIES

Soup-to-Nuts Development

The "soup to nuts" of developing a foster family home can be divided into 5 major areas:

1. Needs assessment
2. Recruitment
3. Initial Inquiry Call
4. Screening
5. Training

1. NEEDS ASSESSMENT

Before starting the search for prospective foster families, it is important to have a clear idea of the needs of the children who need homes. This information helps the developer understand the skills and characteristics he or she seeks in a foster family, and influences the recruitment method used.

It is often helpful for the developer to meet the individuals needing foster homes, and to get to know them as people instead of lengthy and perhaps scary diagnoses. The description to a prospective foster family of Jim as a 12 year old boy with blond hair, big blue eyes, and a big grin who uses a wheelchair is much more appealing and accurate than the description of a white male with Spastic Quadriplegia.

It is crucial that home developers be committed to finding families for every child, as attitudes affect the success of the effort. A developer who, deep in his heart, truly believes that certain children are unsuitable for foster care will convey this to prospective foster families, even if the developer believes he is suppressing these attitudes. Everyone who speaks to prospective foster families must share the philosophy that every child deserves a family.

2. RECRUITMEMT

The goal of recruitment is to generate interest in fostering in the greatest number of people. This is best accomplished by "marketing" the job of fostering. The marketing approach seeks to attract people, and differs sharply from the traditional "screening out" approach. The screening approach challenges the motives of all who apply, and emphasizes the obstacles, bureaucratic steps, and frustrations of fostering in order to weed out people who may not be suitable. In contrast, the marketing approach focuses initially on the attractive personal benefits to a family: work in your own home, make a difference in someone's life, earn $800 a month.

The most common recruitment methods include classified advertisements, radio d television appearances, interviews with print media using existing foster families, news releases, public service announcements, presentations to community and church groups, and direct mailing to target groups.

3. INITIAL INQUIRY

The inquiry call is the first opportunity to expand on the marketing message presented to the public, and to begin to discuss the fostering experience. Many mistakenly underestimate the importance of the inquiry call. The initial telephone contact sets the tone for all future interactions between the applicant and the agency, and sets the "hook" so the good ones don't get away. Having someone available to take calls who knows the program, is enthusiastic and courteous, and who has the time to answer questions and provide information is crucial. Instead of using this call as the first opportunity to screen people out, the MORC goal is to schedule a home visit, and "get our foot in the door." While time consuming, it is better to go out

on unproductive home visits than to overzealously screen out good prospects by phone.

4. SCREENING

Appropriate screening is vital to a good foster care program. Yet historically foster care agencies go overboard. A balance between screening and encouraging and nurturing prospective families is needed. It is unrealistic to expect applicants to be totally prepared and well qualified when they walk in the door. Rather, their potential for growth and development should be evaluated.

Screening generally entails an average of 10 visits to the applicant's home, often after work hours. During these visits the developer teaches the applicant about agency expectations and philosophy, learns about the family's skills and values, observes the interactions of family members, and does an in-depth interview with each person in the household. While MORC is bound by licensing rules which place great emphasis on the health and safety of the environment, our preference is to get to know how the family ticks, and whether they are open, dependable, and trustworthy. Learning their motivation for getting into fostering and the depth of their personal support network is essential. As safeguards, MORC does a criminal history check, obtains personal references, requires a medical statement on every family member, and has a fire inspection of the home, but the biggest safeguard is to know the potential family as well as your own.

5. TRAINING

Formal training serves a dual role in preparing a family while also working as another screening mechanism. Prospective foster families are viewed in a new

context, as part of a group, and are evaluated by different people, the trainers. Home developers may gain great insight into a family by observing their interactions with peers and trainers. Training also builds relationships among new foster families and gives them a sense of belonging to a larger group.

MORC requires about 40 hours of basic classroom training before approving a family for fostering. MORC pays a stipend to the family for their attendance. We find training is most effective when we design it and schedule it for a time most convenient for the majority of trainees. The training uses existing foster care providers as well as staff. Using a participatory style, our training covers topics including normalization, working with birth families, the rights of persons with handicaps, the role of the foster family within the interdisciplinary team, maintaining health, providing medications, and the role of the foster family in the agency. A minimum of 8 hours of ongoing training is required of every foster parent each year.

In addition to pre-service training, child-specific training occurs on an individual basis in the home with a family before the child moves into the home. The length and depth depends on the skills of the family and the needs of the child.

FINDING FAMILIES

Recruitment Strategies

When developing a foster family recruitment plan, we often start with efforts to reach the general public. These may include classified ads, flyers in grocery stores, notices in church bulletins, Public Service Announcements on television and radio, slide show presentations for the civic groups, and Christmas time television interviews with existing foster families. These are all legitimate recruitment methods, and the majority of people who eventually become foster parents initially hear about out program from these sources. Our goal in generalized recruitment is to get the message out to the widest possible audience, using a variety of different methods. Each one must highlight the selling points of fostering.

Ideally the generalized recruitment campaign is widespread, varied, and continuous. Most individuals see several messages about fostering over a period of time before they are motivated to call and inquire about the program. Once the recruitment program is up and running, word of mouth and referrals from existing foster families may also generate successful contacts. But general recruitment efforts are not enough.

We also use targeted recruitment. This contrasts with the general approach as it seeks to reach a particular segment of the population. For example, our goal may be to find families for 25 identified children with severe mental retardation, who have varying degrees of behavior problems, who are active and who currently live in a behavior treatment unit. In this situation, we employ two targeting strategies.

The first, personalized recruitment, takes each child as an individual and a

social map is developed. Every person who is part of the child's life is considered as a potential foster parent. There may be a nurse's aide or cook who already has a special relationship with one of the children, and who, with encouragement and assistance, could become that child's foster family. There may be a teacher who asked permission to take a child home for the holidays. There may be an aide who comes in on his or her day off to feed or visit with one child.

If an individual already knows and cares about a child, he or she is worthy of our energy to receive first consideration as a potential foster parent for the child. In addition to word of mouth recruitment efforts at the targeted facility, other strategies may include putting up flyers, making presentations to staff, arranging for articles in employee newsletters, and putting notes in pay envelopes.

Personalized recruitment is ideal when it works; however, some children don't have a special person in their lives. In these circumstances, we may target a particular group within the general public. If a child has significant health problems, we may focus our attention on nurses and nurse's aides. Our recruitment strategy may then consist of contacting nurses associations about the need for foster families, putting notices in hospital newsletters and bulletin boards, talking to classes of nursing students, placing posters in clinics, nursing homes, and other health care settings, and direct mailings to registered nurses, licensed practical nurses, whose names are available through state licensor bodies.

There is no one method that works every time, so we try as many different strategies simultaneously as possible. Even if one of our efforts fails to

find a foster parent now, it may plant the seed for later harvest. With all methods, it is important to have a consistent message which sells the idea of fostering and emphasizes personal benefits to the family. There is no right or wrong, most successful technique. Whatever works is the key. Frequent, varied, visible, multiple and repetitive messages are the goals.

All of these set the stage for the one that ultimately "grabs". The want ad advertising income may be the first on the list which results in the call or it may have been all the previous messages which let the want ad click.

FINDING FAMILIES

Parental Misgivings

A sometimes difficult part of placing a child may be dealing with the birth family. There is no easy way to wrestle with the very strong and painful emotions surrounding a family's inability to continue to parent a child and the replacement of their role by another family. As painful as this process can be, it is only as unavoidable as the birth family's inability to have the child continue to live with them.

In working with hundreds of families wrestling with this emotionally charged issue, we have learned some lessons about how to help work through the process. Most importantly we have learned that it is possible to reach acceptance from the birth family. It requires gentle but direct confrontation of the issues. The guide through the process has to be someone who has gained a degree of trust from the family. Having succeeded in gaining a trusting atmosphere, we have found the work proceeds through a series of recognitions of the subtle but dramatic differences between birth families and foster families. These differences primarily revolve around the issue of choice. The guide, gently but relentlessly, works through the following comparisons between birth and foster family that impact on the emotional strength each brings to the task.

1. Choice to be a parent to a handicapped child.

   The foster family is entering this area through a conscious planned choice which has rarely been the position of the birth family.

2. Choice of what kind of handicap.

   The foster family exercises some choice in the nature of the disabling condition with which they feel comfortable dealing.

The birth family has no choice.

3. Choice of when.

   The foster family embarks, at a point in time when other elements of their lives are stable and in order. Often times foster families have completed their own families and gotten through the early years of their children's childhoods and are ready and able to devote their energy to the new family member.

4. Emotionally prepared.

   Because the foster family has chosen to have a handicapped family member, they are approaching the event with anticipation and emotional preparedness, unlike the birth family who is often times suffering a crushing experience which depletes their emotional reserves to embark on the rearing of a child with different challenges.

5. Prior preparation

   Since the entry of the handicapped child is planned and chosen, it allows the opportunity for plenty of preparation. Foster families can have training and information about the disability and its prognosis prior to experiencing it. They can prepare the house with modifications and equipment. They can prepare other family members. They can rehearse and adjust their life style in preparation, rather than after the fact without choice.

6. Transition

   The foster child does not just appear one day. There are

descriptions of the child discussed before ever meeting. There is an introduction followed by time to reflect. There are often "trial" visits for the family and child to get to know each other before making final moves. The foster family can take time to reflect and readjust and experience the implications of the disability in gradual doses to the point where they identify readiness.

7. No perception of failure

In the final analysis if a foster family elects not to take a particular child, or even agrees to take a child and later finds themselves unable to continue, the world acknowledges and lauds their attempts. The birth family to the contrary, who elects not to care for their child or seeks to have the child placed, is often viewed with suspicion or even derision for abandoning their offspring. The difference between public reward to foster parents and stigma to birth parents has a psychological impact which should not be underestimated.

By spending time with the birth family focusing on the seemingly subtle, but actually dramatic differences, birth families can begin to take a different view of foster families. This changed perception opens the possibility of acceptance.

The fruition of acceptance occurs only with the birth and foster families meeting each other. Much like the foster family's immediate reaction leading to acceptance of the child, the birth family's immediate reaction to the foster family is often a predictor of acceptance. Just as the foster family's

acceptance of the child cannot be forced, the birth family's acceptance of the foster family cannot be forced. It is often wiser to move on to another family than to force the interaction. In fact, the willingness to consider an alternate family is a strong factor in the birth family's trust of the agency to whom they are entrusting their child. A large number of recruited available foster families is the key that makes an alternative possible.

Since this whole mission is the rearing of a child who is dependent and needing of a nurturing home and cooperation of all supporting parties to that home, it behooves all the parties: the agency, birth family, and foster family to become accepting and trustful of each other. We have found this can be accomplished by taking a gentle but persevering approach.

SUPPORTING FAMILIES

Whatever it Takes Support: Meet Rusty

Having found families who are able and willing, the second major responsibility of the effort is to support the family. To enable them to carry out the mission they have now joined.

Once we have found families willing to accept children, the next step is making it possible for the child and family to live together. This becomes the process of developing a support system. A support system is all the things that make it work. We learned that support is supplying <u>whatever</u> the family needs. Families taught us that it includes everything from financial assistance, training and information to emotional support, modifications of houses, equipment to advice, van lifts, a shoulder to cry on, to someone to share family photographs with, extra hands to help lift, pizza, gasoline, and wallpaper. Once we acknowledged families were "out there" willing to accept children, and that support is whatever-it-takes, we realized that there was no child who couldn't live with a family.

Most difficult for "professionals" to accept was that the family determined what they needed. This doesn't discount the role of the professional in providing advice about what may be helpful. But, ultimately, it is the perception of the family that determines what feels like help and what does not.

Rusty's story describes the "whatever it takes" implication of support that made it possible for one child to live with his willing family over seemingly insurmountable odds.

Meet Rusty

Rusty was born in a rural area in the northern part of the state. Because of the severity and multiplicity of his birth anomalies, he was immediately transported by air ambulance to the University Hospital several hours away. He was diagnosed as having Vader's Syndrome. After many surgical interventions, he was stabilized with a tracheostomy, gastrostomy, colostomy, apnea monitor, and amputated leg. He remained in Intensive Care for seven months before he was stable enough to consider discharge. His mom was a single parent who gave up everything to follow her son to the hospital where she virtually lived with him for seven months. Although now ready for discharge, Rusty needed to remain near the hospital for frequent outpatient care, further surgeries and follow-up.

Rusty's mother was ill prepared to take her son home. In fact, she had no home. She had no income, no transportation, no medical insurance, and no family or friends in the area. The hospital recommended a pediatric nursing home. Rusty's mother visited the proposed placement but rejected it, unable to visualize how her son could grow and thrive in an atmosphere where he competed for the attention of a few nurses, and aides with high school degrees as their credentials, who were responsible for 149 other severely multiply impaired children. Ironically the hospital threatened to pursue court action about her poor judgment regarding what was best for her child.

I became involved with a team from MORC in order to make good on our philosophy of supporting families to enable them to raise their children in family homes rather than congregate care settings.

It was recognized, even by the hospital, that Rusty's mom was a competent care giver. She had thoroughly learned the implications of caring for her son's trach, gastrostomy, cardiac complications, colostomy, and was well versed in techniques to address his developmental delays. The difficulty in having Rusty at home was her inability to provide the care he needed twenty four hours a day without any natural support systems.

Our task was to build the missing elements of support around Rusty and his mom. As a system we had to become her friends and family, her home, her mobility, her financial and emotional support system. Through an aggressive and planned strategy, in concert with Rusty's mom, we were able to arrange subsidized housing, Medicaid eligibility, in-home nursing sixteen hours a day, special education early intervention services, and transportation. Rusty was able to come home.

Admittedly extraordinarily expensive at the outset, as Rusty and his mom settled into their new home and neighborhood and routine, over time services were able to be weaned until Rusty's family's support needs amounted to less than the cost of the pediatric nursing home. More importantly Rusty was eventually rejected from the special education category of severely multiply impaired as he grew and thrived in the nurturing environment of a home.

SUPPORTING FAMILIES

Professional Attitudes: Meet Chelsea

The prerequisite of a child being a part of a family is willingness of the family.

We began to learn with greater exposure to children with complex medical needs, that factors outside the family exercise a great deal of influence on the attitude of willingness and acceptance of the child by the family. Unfortunately, in too many cases, influence was detrimental rather than facilitating. We began to recognize subtle, and not so subtle, influences that undermine families acceptance of a child with seriously compromised health and physical characteristics.

Acceptance is a process that begins right at birth. We found that a role that was missing in typical health care practice was the recognition of the baby as a baby first rather than a diagnosis first. The strongest indicator of families attachment to children with severe disabilities was their perception of the child first as a child, second as a member of their family, and only coincidently happening to have a disabling condition.

For some families, this perception came naturally. These were the families who resisted medical recommendations to find special <u>places</u> for their special children. For other families, the perception of their children was still forming, still malleable, still subject to influence. For these families, the medical recommendations to locate a special <u>place</u> was the most dramatic detriment to the development of acceptance of the child.

The role of a child, when referring to children who are not labeled with

developmental disabilities is easily defined. That is, a child is a young member of a family. When a significant disability is present, this most common and basic role has at times in human service systems been shadowed if not lost. We found that we needed to intervene to be sure the ordinary childness was given at least as much attention as the special needs. In fact, MORC has had to reshape state policy, practice, and regulation to make it mandatory that families hear the rest of the picture before electing a nursing home and when they hear the rest of the story, they rarely choose a nonfamily placement.

The story of Chelsea best exemplifies a "system" response that did not lose sight of this and inalterably change a life history.

Meet Chelsea

Chelsea was born in August, 1985. She was born with an encepholocele. Part of her brain was exposed through her incompletely developed skull. The striking obviousness of this congenital malformation was immediately more apparent in appearance than in function. She was not in danger medically, but the potential for danger was clear in terms of risk of infection or injury to her unprotected brain. Also of concern to physicians attending her birth was the possibility of future disability. It was unclear but likely that other abnormalities such as brain damage existed because of the congenital nature of the abnormal development of her head. All of these issues were the pressing focus of the medical team interacting with Chelsea's parents at the hospital.

Her parents did what people do when confronted with something unknown and health care related. They sought advice from the health care professionals. The health care professionals did what they do when asked for advice about a health-care matter. They gave health care advice. Without their actually realizing or acknowledging it, they also gave non-health care advice. They suggested that Chelsea might have significant special needs and that there was a special place for special needs children, a pediatric nursing home. The parents presented with that advice, absent any other perspective, proceeded to investigate admission for their newborn daughter.

However, serendipitously, the father had a brother who had a friend who worked at MORC and knew something about children with special needs. The father got a phone number and placed a call to the MORC worker. And a different perspective began to unfold. This worker spoke to the family about their daughter, about their baby, about her brother, about her uncle, about their

plans for a vacation, about a future that would include laughter and joy and their daughter. And, oh yes, how special needs can be met within the context of a family.

Some concrete needs were identified. A helmet might be needed which could be paid for through Medicaid funding. Chelsea was eligible for Special Education Services even as an infant to help guide, teach, and advise the family. Life planning through a social worker could help the family plan for a future with an adult daughter with adulthood plans to live outside the family home.

And after a different view of a tiny infant, as a daughter rather than a diagnosis, as a potential aunt rather than an encepholocele, as a family member rather that a special need, Chelsea went home rather than to the nursing home . . . and her parents are thankful for the rest of the picture.

SUPPORTING FAMILIES

Funding: Meet David

Sooner or later every good program idea has to be discussed in terms of its feasibility from a fiscal perspective. One of the beauties of specialized foster care as a model is its cost. Foster care is usually recognized as an inexpensive model of residential care, but it is not often recognized as a model that can serve people with very severe, multiple disabilities. Our experience is that it can and does support children with the most complex medical, physical, and intellectual disabilities. And, if well supported foster families provide healthier, more growth enhancing environments than the most sophisticated intensive treatment residential programs.

Rather than only "acceptable" or "adequate", foster families proved to provide safer, healthier care and children did better than the very expensive settings from which they were placed.

Even though our specialized foster care paid families at a rate substantially higher than traditional foster care for non-handicapped children, and always provided at a minimum an interdisciplinary team of support people, the cost was far less than group homes or institutions.

Our specialized foster care was established with the following funding expectations:

SSI - The cost of room, board, and supervision is covered by SSI. The children are considered a family of one for SSI eligibility purposes. Because of the severity of their handicaps and (except on rare occasion) their lack of personal assets, almost all children in the program are eligible.

Medicaid - The same applies for Medicaid eligibility for coverage of most medical expenses.

In-Home Program - State funds reimburse the family for the paraprofessional training program they implement. This funding covers care and treatment above and beyond the traditional foster care expectations. Rates of reimbursement are established based on the individual needs of the child and the corresponding training plan that is developed in concert with interdisciplinary team. Typical rates of reimbursement for this aspect of the program range from $10 to $35. When combined with SSI this means the foster family receives $25 to $50 per day. Occasionally a situation warrants additional consideration. These funds are considered "difficulty-of-care" funds and therefore are not considered income to the foster family for tax purposes.

I-Team Support - The typical interdisciplinary team of support staff includes a casemanager, psychologist, nurse and occupational and speech therapist. The administrative cost of maintaining such a staff averages out at about $16 per day. (This cost takes into consideration a large program with overhead spread out across several hundred other employees).

Other Supports - The previous categories are minimum cost expectations for all families. Additional supports are added as needed and can include a tremendous range of costs. There are many families who are maintained with costs only from the first four categories. Others use considerably more resources.

Adaptive equipment, ramps, van lifts, and home modifications are high ticket items, but are usually onetime only or infrequent expenses as compared to per diem costs.

In-home nursing is the most expensive additional resource. We have found no child who needs 24 hour in-home nursing on a regular basis, and only a few who have required 16. Most children described in hospital discharge planner language as needing "skilled" care can be successfully and safely served by well trained foster parents with built-in respite relief and identified trained alternate care givers who are other adult family members, neighbors, or friends.

A study[1] undertaken at MORC by Syracuse University Center on Human Policy explored the area of cost comparisons extensively. In an exhaustive fiscal analysis, all public costs were determined for a group of children in foster care who had come from other residential situations. These were compared with the projected public costs which would have been accrued had they remained in the settings from which they came or to which they would have had to go if foster care were not available. The study demonstrates conclusively the cost reductions for children with the most complex needs.

Foster care does not negate the need for hospitalization during acute medical episodes. However there needs to be a distinction between where the child lives and the need for hospitalization. We found children residing in acute care settings who were there, not because they needed them but because there was nowhere less acute, and, therefore, less expensive for them to go. In these cases, foster care had not been considered one of the options. The leap from acute care to foster care seemed too great. And yet, these same hospitals were developing home care plans for children where assertive and competent and well supported birth

[1]Copies of this study are available through James Knoll, DD Institute, Wayne State University, Justice Bldg., Room 326, 6001 Cass Avenue, Detroit, MI 48202, for the cost of reproduction.

parents demanded the opportunity to raise their children at home. David is a child who was living unnecessarily at an acute care hospital because foster care had not been considered. His story is typical of the underestimation of the capacity of foster care families and support systems that enable families.

Meet David

David had lived since birth on an Intensive Care Unit at a major hospital. He was three years old when we met him. He had never lived anywhere else. He was born with a disease very similar to muscular dystrophy in its impairments of muscle movement. It leaves no voluntary movement and even life sustaining muscle movement, such as breathing, is inhibited. David lives only because a respirator breathes for him. He eats only if someone feeds him through the gastrostomy tube in his stomach. And he was having cardiac arrests several times a month. His birth family had no ability or willingness to provide a home for their truly fragile son. Their visits had grown more infrequent over time. The hospital accountant also made it clear that he could not grow up in the hospital.

The search began for an alternate residential care unit less costly than an acute care hospital but sufficiently skilled to deal with sophisticated medical equipment, care, and monitoring. No pediatric skilled care units in the state were willing or able to take on as complex a child as David.

The dilemma of where David should live gave us an opportunity. Approaching David as a three year old boy, we immediately asked why he didn't live with a family. Home care supports are known to be able to be developed to enable children with very complex needs to live with their families. David's own family not being willing, led us to ask about an alternate family, a foster family. Medical discharge planners, nurses, physicians and social workers met at the hospital to discuss alternate placement plans. Our proposal was a family. Their proposal was a residential care facility. They had no facility. We had a family.

The most pressing need was discharge from the very expensive Intensive Care Unit, so they had to listen. And we slowly but surely developed a discharge plan. The foster family had no experience with health care and no credentials other than being good people who loved children, had good child rearing skills, and a willingness to learn. These were the only necessary prerequisites to begin the plan. Everything else David needed was built on this foundation.

The family went through extensive training at the hospital. Their home was outfitted with expensive equipment. Their electrical system was upgraded to support the electrical needs of the equipment.

A home health care corporation was contracted with to provide sixteen hours a

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day of in-home nursing. Their van was fitted with a wheelchair lift. And finally before the final discharge, the family moved into the hospital for a week before discharge where they performed all needed care without hospital staff assistance but under their watchful eye in order for all to be sure they could do it.

It wasn't cheap. The cost of care alone was $200 per day. But that was far cheaper than the $400 plus per day in the hospital. And the equipment and supplies required at home were no more expensive than at the hospital. Despite the high cost, the goal of cheaper residential care was met and David was discharged.

More important to us, and surely to David, however, was the richness of life he experienced beginning on his first day out of the hospital. On the way home from the hospital, he stopped with his foster Mom, and his wheelchair and his respirator, and his oxygen tank to get a hair cut.

David has lived with his foster family now for three years. And as a measure of healthier environment, David has been healthier than he was in the hospital. He has only two cardiac arrests in a year instead of the average 3 per month when he left the hospital. He has had fewer bouts of pneumonia compared to in the hospital. By all medical indications, he is actually healthier out of the hospital than in the hospital. On Sundays he goes to Sunday school.

During the week he goes to school where he plays in the gym with other students. This summer he and his family and their support nurses went camping and sat around the campfire, ventilator and emergency generator and all. David still can't talk or walk or wave his hand or kick his leg or take a breath by himself, but his eyes sure say a lot. It seemed pretty clear he liked camping better than the Intensive Care Unit.

SUPPORTING FAMILIES

Casemanagement: Meet Karen

Casemanagement is a support service we have come to feel is integral to the success of the program. Casemanagers are the folks who are assigned ultimate responsibility to oversee that the individual child is getting all that is needed in the best possible living situation. The casemanagers job in foster care is to make certain that the placement "works". They need to see the home and relationships and learning opportunities through the eyes of the child. They need to nurture and support what is good and mold and shape what could be better. They are the holder of the responsibility for testing the quality of life of the foster child. Once having assured the rightness of the choice of family and the connection of a bond of parent and child, they are then the key source of support to the foster family to make it work. They must get the family what it needs, whether equipment, information, helping hands, or professional advice. And as importantly or more importantly they need to be there in the living room with the family often and whenever the families need it. To make this role feasible, we have found it necessary to modify our working conditions for casemanagers. Caseloads have been set a maximum of one to 24 clients and the work week includes evenings and weekends scheduled as a condition of employment. The conditions of employment are set so the message is very clear to staff as well as foster parents, that a family's life style is more important than the bureaucracy's schedule, and it is we who must adjust to them.

Casemanagement is one of the buzz words of the 80's. We are no stranger to the merits of casemanagement, but like many buzz words, we're no longer sure

the word casemanagement, as used commonly elsewhere, conveys what we intend.

Karen's story highlights dramatically, what we expect of casemanagement if it is truly a support to families.

Meet Karen

Karen came to the agency right out of high school. Her position was a clerical position in a what was then a new agency. Karen entered the atmosphere of an agency which had a driving sense of mission which took frequent opportunities to celebrate the joys in the success of life styles we were helping to unlock for people with developmental disabilities.

Karen fell in love with the mission and returned to school to get a bachelors degree so that she could become a casemanager. As soon as she had her degree, she was accepted in the position of casemanager in the foster care unit. She went back to school to work on a Master's degree in Social Work to improve her skills and insights in working with families.

Donna got her position in casemanagement shortly after Karen. She too went back to school in social work while working as a casemanager. Both Donna and Karen were known as hard workers. They developed good plans of service for their clients, and completed annual, quarterly, and monthly review reports in a timely fashion. Their written documentation was clear, concise, and they were responsible to parent and guardian concerns. They communicated with other members of the interdisciplinary team. They processed budget authorizations appropriately. They returned phone calls and followed up on issues as needed. Both Donna and Karen graduated the same month and were the proud holders of MSW degrees.

One afternoon I had an important message from each that they needed to see me that afternoon. I called Donna in first. She sat down and somewhat reluctantly indicated that she would be giving her two week notice. She indicated that she enjoyed the work at M.O.R.C. and the people she worked with, but felt she was not able to use her new degree, as the casemanager position did not require Master's level skills.

I called Karen in shortly after my discussion with Donna. Karen's need to see me had also indicated a degree of urgency. She sat down and somewhat reluctantly indicated that she was feeling that she had run out of options in securing services for one of her families and asked if she could borrow my pick up truck. She had arranged for a birth family to have their daughter home for an extended visit which could lead to her possible return home, but the birth family needed to move some furniture and equipment to make it possible. Karen indicated, if she could borrow the truck overnight, she would go help the family move the stuff that evening so their daughter could come home the following day.

I remember marking the commitment Karen felt to the child and her family and

wondering why Karen could see so clearly a role for herself which Donna could not. Donna knew her cases. Karen knew her families. Donna knew her plans of service. Karen knew the mission. Donna knew the service system. Karen knew what-ever-it-takes.

GOOD-BYE

Rules for the Road

We thank you for your interest and hope you have enjoyed your visit with us. We're glad to have had the opportunity to introduce you to some of the people we know who have taught us so much. As we leave you here to return home and take up the mission, we want to close with a few suggestions for the journey. Somewhere in your visit we hope you saw these road signs. We realize there's a lot to experience in a short visit. If you missed one of these signs, maybe you'll go back and revisit some of the folks you met and watch for the sign.

1. It's not easy.
2. It's about <u>acceptance</u> of all people.
3. There is a <u>demand</u> for handicapped children that exceeds the supply.
4. It requires a change in the way people think.
5. There is no rule book.
6. There are myths connected to medical care.
7. There will be conflicts and controversy when people work with people.
8. The system can't be trusted for the answers.
9. Our own expectations influence how we react to families and kids.
10. You must face life and death issues.
11. Life is worthwhile for all people. The feeling that some children are better off dead denies their value.
12. Smaller is better but not good enough. Only a family is good enough.
13. Kids bring out capabilities we underestimate.
14. Communication to a Mom is a safer care situation than communication to multiple licensed nurses.
15. Words get in the way.
16. Personal attitudes undergo an evolution of change.
17. There is hope.
18. Networking does work when systems don't.
19. A kid is more than a diagnosis.
20. Fragileness is a myth.
21. Everyone is cute to someone.
22. Obstacles are just things to be overcome.
23. Kids are kids.
24. No kid is too tough.
25. People change.
26. You can't plan for real kids without actually touching them.
27. Clothes make the person, or at least can make a big difference in the way we perceive people.
28. Families are resources right under our noses.
29. A family is not always Ozzie and Harriet.
30. Support is whatever it takes.
31. You have to work to make the system work.

32. Love at first sight is a real phenomena.
33. A child is waiting for us.
34. There are people under all those medical labels.
35. Readiness is a myth.
36. There are many typical families handling very special health care needs.
37. Parents are competent, sometimes despite tremendous odds against them.
38. Based on first impressions, some of our best foster families would not have made it.
39. It's work but it works.
40. There is chemistry at work.
41. Families grow too.
42. Perseverance is a requirement.
43. Personal involvement above your job description is required.
44. We don't tell the family what support is, they tell us.
45. Support sometimes means help to confront the system.
46. The shortage of families is a perceptual error.
47. You gotta ask.
48. You gotta listen.
49. Kids are kids are kids.
50. There is a family for every child.

Many folks in the human service community have come to agree on the importance and quality of foster care for some disabled children. But even the strongest of foster care supporters experience doubt about <u>some</u> kids. And that includes many of us at MORC from time to time. Fortunately the capacity of families reminds us that the doubt is our own perception of what <u>we</u> might be willing or able to do; not the perception of the right family about the child.

There is the right family out there. If they haven't yet been found, it's because you haven't looked hard enough. There are millions to choose from. Some have just not yet had the opportunity of being asked.

GOOD-BYE

Then and Now: Meet Krista

Then

. . . As an 18 year old student doing a pediatric rotation at Children's Hospital in 1968, I met Baby L. She was approximately 3 weeks old and had a chromosomal disorder which resulted in a multitude of external and internal malformations. I tentatively touched her and finally found enough guts to pick her up. That was really scary because her head was enlarged and I thought I would hurt her. I took her to a rocking chair and sat down. Soon she settled down and started nuzzling at my breast. I started to feed her by bottle and she contentedly sucked at the nipple. Soon after we were intruded on by a group of three men, a resident, intern and med student. They started talking amongst themselves. I heard " . . . transillumination", ". . . amenocephalic", ". . . Trisomy 13-15", ". . . flashlight", ". . ."closet." Would I mind taking the baby in a closet where one at a time they would shine a flashlight on her head? Since nursing students were considered subordinate, I followed orders. The closet was small and of course dark. As I stood holding this child, the doctor shone the flashlight close to her skull. Her head was transilluminated. The doctor told me this was because the baby had only minimal brain tissue, basically only brain stem tissue housing respiratory and cardiac functions. Baby L was discharged within the next two weeks. I asked discharged where? The response was "You know, one of those institutions for retarded kids". So much for discharge planning in 1968.

Now

Kristen is seven years of adorable. At first glance, she reminds you of Pebbles, the Flintstones' pride and joy. She is adorned with miniature jewelry and is decked out from head to toe. Her barrettes match her socks. She has a designer wheelchair trimmed with pink ruffles. Kristen has made lots of friends at school and fusses when she isn't part of the group. She smiles and teases; kicks and wiggles to knock her toys to the floor so you can pick them up. She is a full-fledged member of her family who adopted her after she was placed in their care as a foster child.

Quite a different scenario from the bleak picture described for her at birth. Her family met her in September of 1982 when she was three months old and still in the hospital where she was born. The notation in her chart for discharge planning read, "looking for foster care which probably won't happen so will need to be institutionalized." The family's first introduction to her went something like this . . . "She doesn't have any brain and she doesn't like being touched or held. Do you know what you're getting yourselves into? This baby will be totally unresponsive to you and will do nothing but lay there and cry."

The neurologist put a flashlight to her head and said, "See, there is nothing there; she is little more than a pet. These children are not worth saving.

Let nature take its course". The learned physician clapped his hands, and although Kristen startled, declared she was deaf. He waved a metal instrument in front of her face and diagnosed blindness. But Kristen's family saw something else.

Kristen's life has been worlds apart from her original sentence of imprisonment while awaiting death. Instead, she has a family who loves her enough to make a life for her.

A life well worth living because brain tissue is not related to heart tissue.